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ABSTRACT

This Task Force on Privacy and Confidentiality is intended to call attention to the central role of the right to privacy in the maintenance and enrichment of a free society. The psychological implications of the changing views of privacy as reflected in political, social, and technological developments are discussed, and recommendations relating to legislative and judicial developments in the areas of privacy and confidentiality are given. The task force also considers the impact of such developments on psychologists and those whom psychologists serve, such as therapy patients and subjects of psychological research. (Author/JLL)



Final Report

APA Task Force on Privacy and Confidentiality

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Preface

The mission statement for the Task Force on Privacy and Confidentiality was as follows:

The mission of this task force will be to call attention through appropriate means to the central role of the right to privacy in the maintenance and enrichment of a free society. The task force will engage in a study and make a report on the psychological implications of the changing views of privacy as reflected in political, social, and technological developments. It will also monitor and make recommendations relating to legislative and judicial developments in the areas of privacy and confidentiality.

The task force will also consider the impact of such developments both on psychologists and those whom psychologists serve, such as therapy patients and subjects of psychological research. Special attention will be paid to groups especially likely to be subject to questionable invasions of privacy, e.g., children, prisoners, and mental patients. Consideration will be given to reconciling the need for legitimate scientific research, including the evaluation of social programs, with the right to privacy, through stringent safeguards against violations of confidentiality. Subsidiary issues such as testing and informed consent will be considered, and attempts will be made to encourage research in the areas of privacy and confidentiality. As needed, guidelines relating to specific issues within these areas will be developed and presented to the Association for consideration.

Somewhat to our surprise we find that we have done at least a little on all of the subtasks mentioned. This report summarizes the thinking of the Task Force.



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Summary of Recommendations

- I. As the official voice of Psychology, the American Psychological Association should create or strengthen mechanisms for stating psychology's position in connection with widely publicized invasions of privacy and other infractions of our ethical guidelines. The responsibility for implementing this guideline appears to lie in the Central Office of the Association.
- II. The American Psychological Association should use its official voice and devote some of its resources to the encouragement of research on privacy and confidentiality.
- III. In those areas where statutory protection for clinical-therapeutic and other personal data exists that protection should be strengthened and refined.
- IV. In those areas where administrative records are protected by law, the law ought to be refined to recognize that in many instances those records serve as a basis for important statistical research.
- V. In those areas where statutory protection for research records exists, the statutes should be strengthened and refined.
- VI. In cases where a therapist could also be involved in administrative decisions about a client the therapist should, if possible, remain apart from the administrative decision.
- VII. Personally identified mental health information should be retained by the facility that obtained it. No other agency should be allowed access to information in this form.
- VIII. Possibly through the creation of a new section in the <u>Monitor</u> a forum should be established for the discussion of practical ways of resolving problems which bear on the confidentiality of personal information and the privacy of the individual.
 - IX. As practical experience in the area of privacy accumulates, APA should



commission the preparation of a <u>Casebook on Confidentiality</u> where concrete examples of dilemmas and solutions could be made available to the membership.

- X. Sophisticated techniques now exist for the collection of sensitive data in ways that insure respondent's privacy. These should be brought to the attention of people in the field.
- XI The Board of Directors of the American Psychological Association should appoint a new Task Force on Privacy and Confidentiality.
- XII. This Task Force on Privacy and Confidentiality should be dismissed. This report or some summary of it should be made available to the membership of the American Psychological Association and to the people in other fields concerned with these issues.



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Introduction ,

Human concern over the protection of privacy and the maintenance of the confidentiality of information obtained about people has a long history. The concern is an important one because it derives from fundamental considerations related to our conception of the nature of society and even human nature. It has been said that a free society is governed by the principle that there are regions of existence, not artifically established, within which people should be inviolable, these regions being identified with rules so widely accepted that their observance has entered in to the very conception of what it means to be a normal human being. This concept of inviolability makes the right to privacy a sacred right—not in the religious sense, but in the more basic one of set apart and untouchable except by special people.

Over the years our perceptions of the boundaries of these inviolable regions has changed. Justices Warren and Brandeis writing in 1890 made the point this way: In early times privacy laws served mainly to protect people from physical interference with life and property. By the end of the last century, these laws had become concerned with the "right to be let alone," and with the protection of the individual's "inviolate personality." Now this concern has broadened to include information about people in a wide variety of contexts.

In recent times the issues of privacy and confidentiality have taken on an increased intensity largely because of the rapid growth of computer technology for the storage and retrieval of personal data. Federal governmental agencies acknowledge the existence of some 6,723 data banks with information on 3.8 billion persons (obviously duplicate or even "n-plicate" records must exist on many people). Of these, 831 are maintained by the Department of Health, Education and Welfare. In addition, state and local agencies, insurance companies and financial and credit institutions maintain files. With specific regard to health-related files, Blue Cross/Blue Shield and the Medical Information Bureau maintain data on the health

and illness histories of 60 to 70 million individuals in rapidly retrievable form. Governmental agencies such as Social Security, Civil Service Commissions and Health Departments have millions of records that contain information on alcohol and drug use and treatment for emotional problems. The obligatory reporting of child abuse (suspected or confirmed) has added another central registry. The Multi-state Information System, contains complete mental health histories and links psychiatric hospitals, clinics and outpatient health centers in the New England area. Medicare, Medicaid, and other public health programmers already are keeping millions of health records. The Medicaid Management Information Service alone contains medical and eligibility files on more than 20 million impoverished Americans. The new PSROs (Peer Standards Review Organizations) will add their demands to those of government insurers and cost justifiers. They will need vast amounts of personal information to guarantee in various ways that medical and health services rendered by the Medicare, Medicaid and maternal and child health programs are necessary and of high quality.

Consequences in Legislation

A general concern for this state of affairs and proposals for remediation have been expressed in legislation, special conferences, and position statements. In 1973, the Secretary's Advisory Committee on Personal Data Systems of the Department of Health, Education, and Welfare issued a report entitled "Records, Computers, and the Rights of Citizens." This served to stimulate the passage of the Privacy Act of 1974 in the closing days of the 93rd Congress. This act established a Privacy Protection Study Commission charged to study data banks and information-processing programs in the government and the private sector and to submit a final report aid recommendations to the President and Congress by June 10,1977. Other federal legislation also included sections on privacy. For example, the Education Amendments of 1974 contain a provision giving a parent and/or student the right of access to



educational records. The Crime Control Act of 1973 limits the use of criminal records and permits correction of erroneous data. In the 94th Congress, over 60 bills on privacy and related issues were introduced. The areas covered by the bills include criminal justice, consumer credit, access to the records of private organizations, wiretapping and surveillance, limiting use of polygraphs in government and private sectors, and income tax. Minnesota, Utah, Arkansas, Massachusetts, Virginia, and Ohio have enacted laws regulating government data banks, modeled with variations after the principles of the federal Privacy Act of 1974. Others will surely follow.

Actions of Professional Organizations

Professional organizations also have addressed themselves to these issues. A Position Statement on the Confidentiality of Health Records was adopted by the Board of Directors of the American Orthopsychiatric Association in March of 1975. On the initiative of the American Psychiatric Association, some 16 national organizations formed the National Commission on the Confidentiality of Health Records. A conference was held in Key Biscayne, Florida, November 6-9, 1974 and the first official meeting was held on December 4,1975. In June, 1975, the American Psychiatric Association established a Committee on Privacy and Confidentiality. The National Academy of Science-National Research Council's Committee on Federal Agency Evaluation Research devoted its final 1975 report to Protecting Individual Privacy in Evaluation Research. Also, in 1975, the Board of Directors of the American Psychological Association established this Task Force on Privacy and Confidentiality. Undoubtedly this chronicle is not complete, but it is sufficient to attest to the general feeling of urgency "that something must be done" to guarantee the individual's right to privacy.



Studies by the American Psychological Association

For some 30 years the American Psychological Association has concerned itself formally with ethical issues including those of privacy and confidentiality.

Obviously the beginning of this formal involvement means that informal concern must have been growing before that. In any event, in 1947 a committee headed by E. C.

Tolman recommended to the APA Board of Directors that an empirically derived code of ethics be developed for the guidance of psychologists. In 1948 the Board appointed a new Committee on Ethical Standards for Psychology, chaired by Nicholas Hobbs.

By 1952 the Hobbs Committee had prepared a comprehensive document which covered ethical standards in a wide range of psychological activities. This report was published during the following year and was the first of a series of APA publications on matters of ethics.

Orienting Commitments

The position of the American Psychological Association on ethical matters consists of two components: a set of underlying philosophical commitments and a set of more specific principles, standards or guides to ethical psychological behavior. The first of these components is basic to the second and will be presented first. Much of the language in this section comes from the introduction to the APA publication Ethical Standards for Psychologists.

1. Psychologists believe that ethics are important. Because human beings are the focus of our science and the users of our services the psychologist is constantly involved in problems of ethical import. As evidence of the seriousness with which psychologists take such matters we cite the fact that over 2,000 psychologists were sufficiently concerned to contribute substantially to the formulation of the 195, code. Although the figure is harder to estimate, a much arger number of psychologists (drawn from an enormously larger APA twenty years later) contributed in some way to Ethical Principles in the Conduct of Research with Human Participants. A



conservative estimate is 6,000 individual psychologists.

- 2. Psychologists believe that the ethics of the discipline cannot be prescribed by a committee but must emerge from the day-by-day decisions and value commitments made by psychologists in their profession.
- 3. Ethical behavior, like other behavior, can be studied objectively. The several sets of ethical standards developed by APA have resulted from an application of the methods of social science.
- 4. Ethical behavior requires a form of conflict resolution because ethical decisions pit certain values against others. For example, the decision of whether or not to protect the privacy of psychological information about an individual requires that the psychologist weigh the value of privacy against the good that might come to the individual or society if the person's privacy were violated and the harm that might come if it was not.
- 5. In the ethical decision-making process, there are no ethical absolutes. Ethical judgments always involve a consideration of the alternatives in specific contexts. Moreover, the elements of ethical conflicts can vary in seriousness. There can be small or large invasions of privacy, breaches of confidentiality, deceptions, degrees of coercion and the like. These matters of degree contribute to the decision of whether a particular procedure or practic is ethically acceptable.

This relativistic position leaves many psychologists with a feeling of troubled discomfort. Somehow it seems that ethical principles ought to be absolute. No doubt most of us would feel more at peace with principles that took a more definite stand. But every group that has considered the ethical problems of psychology has been forced to the relativistic position by the detailed and intricate nature of the ethical problems psychology faces.

6. A code of ethics must be more than a description of current ethical practice in a profession. A code must embody ethical aspirations and encourage



changes in ethical behavior that will bring it ever closer to these aspirations.

- 7. The development of ethical standards must be a continuing process if ethical codes are to apply to current situations.
- 8. In the encouragement of ethical behavior, practice is more important than pronouncement. The participation of thousands of psychologists in the development of our ethical codes is counted on to have more influence than published statements in changing ethical practice.
- 9. The making of ethical decisions is the individual responsibility of the individual psychologist. Since these decisions often involve matters of high personal importance, however, there will be times when the psychologist will want to avail himself of the advice of others such as trusted colleagues and institutional review groups.

The Empirical Method of Developing Ethical Codes

In 1947 the Tolman committee recommended an empirical approach to the problem of developing an ethical code. The method finally developed began by asking a large sample of APA members to submit examples of incidents (solutions as well as problems) that seemed to pose ethical questions. This request provided the committee with a substantial number of examples of ethical problems. The next step was for the committee to sort these examples into meaningful categories, the basis for sorting being the ethical issue represented. Eventually these categories were to define the topics for which ethical principles would be written.

The development of such categories is never easy because the examples seldom report pure cases of single ethical problems. Moreover the nature of the categories depends upon the range of ethical issues sought in the survey. In the case of privacy and confidentiality, for example, these concepts appear in everal different categories in the Hobbs report, which dealt with ethical problems in a very general way. In the Cook report on research ethics, by contrast, privacy



and confidentiality appear together in a single category. Probably two factors account for this difference: 1) The greater generality of the task being performed by the Hobbs Committee led to a set of categories defined in terms of particular types of professional interpersonal relationships: research, professional practice, teaching, writing and publishing. The responsibility of the Cook Committee, being limited to the first of these activities, made it possible for a more finely differentiated set of categories to emerge. 2) By the time the Cook Committee began its work, privacy and confidentiality had become matters of insistent social concern.

With the categories of ethical issues established the next step has been the writing of a first draft of a set of ethical principles. These have been offered to the membership of APA for discussion, criticism and amendment. Following what has typically been widespread discussion of the tentative principles, a final draft has been prepared for submittal to the Council of Representatives for approval.

Principles on Privacy and Confidentiality

The methods just described have produced several statements on privacy and confidentiality. The various versions of these principles are in general agreement on points that can be summarized fairly succinctly.

- The psychologist has an obligation to safeguard information about people obtained in the course of his professional activity.
- 2. The obligation to protect privacy extends into the future and requires the psychologist to provide for the custody of records in order to maintain the confidentiality of psychological information.
- 3. The obligation to protect privacy extends to the colleagues, assistants and employees of the psychologist.
- 4. Psychological information about a person should be discussed only with people who are concerned for the welfare of the individual and are qualified to



understand the information and use it, if at all, for the good of the individual or society.

- 5. If the possibility exists that information will or must be divulged this possibility should be explained to the individual and his consent received prior to such disclosure. This requirement is particularly important where negative information may have to be given to legal authorities.
- 6. It is essential that information passed on about an individual, when that is required or expected (e.g., in letters of recommendation), be accurate. Where doubts about the accuracy of information exist the bases for such doubts must be a part of the information transmitted.
- 7. The individual has a right to know the results of psychological evaluations obtained upon him. The psychologist providing such information to the individual has the obligation to present it in a form which will allow the recipient to interpret it in a meaningful way.

Implementation

The standards and principles developed by the APA over the years have served psychologists well. A Committee on Scientific and Professional Ethics and Conduct implements the rules. In the last 8-10 years this committee has dealt with something like 400 cases of alleged violation of the ethical code, with a variety of outcomes. In some cases the Committee concluded that no ethical violation existed. In a good many others Committee action had led to a correction of an ethically questionable practice. In a few cases a psychologist has received a reprimand and, in still fewer, unethical activities have led to a member's being dropped from the Association. One cannot read the minutes of the Committee meetings without being impressed by the fact that good sense and constructive approach to problems have always marked its deliberations. It is probably also important to mention that after a peak in 1971 the number of cases considered by the committee appears to have undergone a sharp decline.



The fact that the ethical situation is well in hand does not mean that a relaxation of vigilance is in order, however. From the beginning of its concern with such issues, the APA has taken the position that the development of ethical standards must be an ongoing activity. For reasons that are implicit in this position it will be important, from time to time, to review the APA's position and to ask whether the time has come to set forth new principles or to amend old ones. Such considerations in the areas of privacy and confidentiality will come up from time to time in this report.

Privacy and Law

Privacy and confidentiality become legal issues because of the frequency with which conflicts arise between the individual right to privacy and the right of institutions to invade it for purposes that serve the common good. This conflict goes back to ancient times. Greek, Protestant and Anglo-Saxon law emphasized the first of the rights; Roman and Catholic traditions emphasize the second. In more recent times, vast changes in the world have intensified the problems related to privacy and confidentiality. Government has grown and now enters the private lives of citizens in a way that would have been unthinkable a few decades ago. Business enterprises have expanded to the point where the giant corporations have all but done away with individual private enterprise. And, especially, information technology has developed in ways that make it possible to collect, store and distribute a wide range of data on the mental, physical and financial circumstances of people. The new technology functions in the service of big government and big business and this is a part of the background against which a growing concern for privacy has developed.

Another part of the background is attitudinal. This is a time when the established institutions have suffered a great loss of credibility. The fact that personal bank records and medical records are available to almost any official agency has received wide publicity in the media. Scandals involving the White House,



Lockheed, IRS, CIA and FBI and the medicare program suggest to many that the goals of these institutions are scarcely those of promoting the public's welfare. The idea that large organizations with sometimes malevolent objectives possess the technology to obtain vast amounts of personal information to use as they will is frightening.

Finally, there is a related point. As the world has grown more complex the activities of government, business and the professions have become harder to understand. What one cannot understand one cannot control and losing control makes one vulnerable. Given the image of public institutions with anti-public goals in possession of vast stores of personal data, it is not hard to see why the violation of privacy has taken on the aura of personal danger.

Impact on Psychology

Reflections on the position of psychology in this troubled scene do not lend to feelings of comfort for two reasons. First, mental health information, so important to the field, is at the top level of sensitivity. Such information is one of the last things that most of us are willing to have made public. Second, both the ethical and legal status of psychological information are unclear vis a vis the issue of confidentiality. Ethical codes are being reviewed and legislation in the area of privacy is being developed in most, if not every state, in the union.

The Right of Privacy in Mental Health Care

The case can be made that the constitutional rights of individuals impose limits on the collection, compilation and sharing of personally identified mental health information. For example, the Supreme Court has held certain rights related to mental health confidentiality to be protected. In reaching these decisions the Court has indicated the elements of the right to privacy and it would appear that several aspects of the mental health care situation would include those elements.

One of the chief factors on which the Court has focused in reaching its decisions has been the individual's right to make decisions concerning important personal matters,



for example, matters so fundamentally personal as arise in connection with marriage, procreation, contraception, abortion, family relationships, child rearing and education. In other decisions the court has extended the range of this right of privacy to cover other intimate relationships. These include non-familial relationships, particularly those with one's doctor.

A further point of emphasis in deliberations by the Court has been on the concept that decisions regarding one's health are intensely personal decisions. For example, the Court has recognized a pregnant woman's constitutional right to make the abortion decision on the advice from her own physician, without the approval of a hospital committee, the concurrence of other doctors or the permission of a spouse or patient.

Evaluated against the criteria implicit in these rulings, health care decisions seem to be covered. Two of the basic factors outlined by the Court in defining constitutionally protected privacy -- fundamental personal decisions and intimate relationships -- are always present in the mental health care situation. The individual's right to seek and continue mental health care and treatment should, therefore, be considered to be constitutionally protected; and statutes and practices which infringe upon the individual's prerogatives the area of mental health care and treatment should be viewed as invasions of the constitutional right to privacy.

Effects of Privacy Violations

The right to personal autonomy in health-related decisions takes on special meaning in the context of therapy. This consideration has played a part in litigation.

Patients and parents have testified as to the negative impact of statewide reporting and electronic databanking on their choices of treatment. In two separate instances, parents testified that they discontinued a prescribed chemotherapy of their children because it resulted in the reporting of their children's names (and their treatment) to a statewide computerized databank. Likewise clients of mental health outpatient clinics have testified that they would not have entered therapy if they had known of



a requirement that their names and certain treatment information would be compiled in a statewide electronic data bank. Physicians and psychiatrists have also testified in these cases that their patients had been adversely affected by such data collection requirements and that some individuals would be dissuaded from treatment.

In the case of mental illness there are obvious reasons that one of the possible consequences of disclosure and record keeping requirements would be to discourage treatment. Persons labeled "mentally ill" often face destructive social stigmatization. Many people have an irrational fear of the mentally ill. Others have feelings of distrust and dislike. A former mental patient may be socially ostracized, lose his job, have his insurance discontinued and find himself discriminated against in efforts to obtain new employment or further his education.

These effects are serious enough to lead people to avoid necessary treatment out of fear of disclosure. And there are reports that the mere threat of disclosure can undermine the therapeutic relationship when the individual learns that such a possibility exists.

To summarize, the constitutional right to privacy can be viewed as including the right to personal autonomy in mental health care and treatment. Therefore, to the extent that information systems deter the individual from seeking such care or interfere with the therapeutic relationship, they infringe upon the right to privacy.

Confidentiality of Health-Care Information

In addition to protecting the individual's freedom of action in therapeutic relationships, the right to privacy may be viewed as protecting the client's right simply to keep certain highly personal and sensitive information confidential. In a right-to-abortion case, the Supreme Court has held that the fact of, or a woman's reasons for, abortion are so private that such information is protected just as the right to make the personal decision to have the abortion is protected. It is reasonable to expect that the Court would be equally as concerned for the privacy interests of mental patients. In fact, given the historical sources of the right to privacy,



it may be expected that, when that right is eventually more fully defined by the Supreme Court, the intensely personal and sensitive nature of mental-health information, the need for confidentiality in the mental-health therapeutic relationship and the potentially destructive aspects of disclosure will guarantee the individual's mental-health diagnostic and treatment information a place in the very core of protection.

Justified Infringement

The right to privacy, like other constitutional guarantees, is not absolute. It must be considered against other important social interests. Court decisions have held that, when these interests become sufficiently compelling, limited incursions upon the right of privacy may be justified. For example, physicians have a duty to report epidemics and some communicable diseases. It is important, however, to stress the fact that it is not enough that some legitimate basis for infringing fundamental rights like privacy exists. There must be compelling reasons for such infringement.

The Least Drastic Means Requirement. Even when the state has a sufficiently strong interest to warrant an invasion of privacy, the infringement must be no more than is necessary for the achievement of the state's purposes. Often referred to as the least-drastic-means test, this principle prohibits the use of means that encroach upon fundamental rights to a greater extent than alternative means that would allow the government interest to be attained.

Many governmental information systems including personally identified mentalhealth information appear to be vulnerable to litigation under this principle. Too
little concern has heretofore been given in the design of information systems to the
privacy interests of individuals. Challenges to disclosure and compilation requirements and practices could seek greater use of statistical reporting and anonymous
records which do not permit patient identification. They could also argue for spot
checks of individual cases in place of wholesale reporting, and the stripping of
personal identifiers before the transmission of data to centralized files or electronic
data banks. These few examples of less drastic means would apply primarily to mental-



health service systems.

A good illustration of the application of these principles is provided by a case where the plaintiffs sought relief from a statutory requirement of statewide reporting and central computerization of patient-identified information regarding prescriptions of "Schedule II" drugs, i.e., certain narcotic and other drugs commonly involved in illicit drug sales. Prior to its final decision, the three-judge district court declined to issue preliminary relief because it was not convinced that the consequences of the resulting intrusions were not justified when considered against the state's interest. But at an evidentiary hearing the plaintiffs had the opportunity to demonstrate that the computerization of names was not necessary for the accomplishment of the state's goals, that the controls developed by the state were inadequate to protect against unauthorized disclosure of the computerized information and that the injury to the plaintiffs resulting from the implementation of this system was sufficiently serious to overcome the competing state interest. When the court considered the evidence it was persuaded that the state regulatory scheme -- although fostering a legitimate state purpose -- had a needlessly broad sweep.

The district court in this case found that the sole purpose for collecting the names of patients was to identify individual patients who, without using an alias went from doctor to doctor to secure Schedule II drugs in order to obtain more than a 30-day supply in a single month. The court also found that the state's need for the names was illusory, as evidenced by the fact that only one person suspected of having secured multiple prescriptions in a particular month had been discovered during the program's four-year existence. As a matter of common sense, it is unlikely that a person seeking to hoard drugs for personal consumption or sale would use his or her real name and address, or use the same name each time he or she visited a different doctor. The district court thus determined that the infringements on privacy were too great a price to pay for such a small governmental yield.



<u>Waivers.</u> When a socially valuable interest would be served, citizens may waive their constitutional rights. Such relinquishment of individual interests to the state, however, must generally be knowing, intelligent and voluntary. Waiver principles are closely akin to the concept of "consent," with which mental-health professionals are more familiar.

Under these principles it seems clear that a mental patient, upon receiving information about the possibility of disclosure and the use to which the data will be put, may authorize the release of information outside the treatment facility. How well advised he must be, how complete his understanding of the situation must be, and the nature and extent of coercive influences which would invalidate his waiver, however, are questions on which existing constitutional precedents provide little guidance. There has been too little litigation in this area to draw any firm conclusions. Obviously, the extraction of a waiver as the price of obtaining treatment raises questions about the validity of the waiver.

Conclusions

The foregoing discussion may create the impression that constitutionality oriented litigation can be relied upon to provide adequate protection for the mental patient's privacy. Such an impression would be seriously mistaken. For numerous reasons, litigation is nowhere near the complete answer. It is expensive, and time-consuming. Some of the principles stated above are not firmly established and all are subject to misconstruction and other interpretations at both trial and appellate court levels. The necessary expert testimony needed to "make the case" can be difficult to marshal at times.

Beyond these generally practical issues, there are inherent limits on litigation based on constitutional claims. All of the principles discussed above involve "balancing tests" whereby the individual's interests are weighed against those of the state and the means which the state has chosen to achieve its purposes.



Accordingly, there may be many instances in which, as a matter of constitutional doctrine, intrusions upon privacy are permissible but policy considerations call for greater safeguards. Legislatures and state agencies typically have a range of choices within the bounds of what the Constitution allows. Not everything which the Constitution allows is wise or as fair as desirable.

Moreover, constitutional restrictions generally apply only to governmental practices. Vast privacy concerns exist with regard to the practices of insurance companies, employers and others in the private sector who are beyond the reach of constitutional limitations. Legislation is needed to protect the individual in these areas.

A strong indication of the limits of litigation is the fact that the problem currently exists. Were lawsuits a sufficient tool for the resolution of privacy issues, we would not now be grappling with concerns over the excesses and abuses of governmental and private information systems. Beyond the Constitution, statutes and regulations, there are abundant opportunities (and also moral responsibilities) for psychologists and other mental-health professionals to serve as advocates of confidentiality. In various day-to-day situations, in a great variety of supervisory capacities, and in their many contacts with information systems, professionals can effectively shape the boundaries of privacy and confidentiality in the world of practicality and influence.



Psychological Aspects of Privacy

Privacy is a concept related to isolation, seclusion, and freedom from unwanted observation. But it is also more than that for it implies autonomous control over the right of access to the realms of personal experience. As the concept has been interpreted legally and ethically it has come to be almost synonymous with human dignity and personal integrity.

Much of the current concern in the area has involved the extent to which there is a constitutionally guaranteed <u>right</u> to privacy. Some of the relevant considerations in this area have already been presented. As psychologists, however, there is another aspect of privacy to which we should turn our attention, the human <u>need</u> for privacy which gives rise to ethical codes and laws. It seems appropriate, therefore, to ask about the determinants of desires for privacy and the modes of expression of this need. In asking about such matters we are raising questions that might be answered by empirical research.

Research in the area of privacy is just beginning. Progress is hampered by the fact that such investigations still have to define the area to be studied. Only a few scholars have done research on privacy and those who have come from disparate fields of social science. Perhaps a brief discussion of some major trends in the area and a treatment of some of the issues will encourage additional investigators to initiate research in this important area.

Origins of the Need for Privacy

Possibly the most basic fact leading to the development of a need for privacy is the obvious one that not everything is knowable to everyone. Total sharing of experience between individuals is impossible. This means that some people will have knowledge that others do not and this leads to concern about how that knowledge is used. The assumption of such unshared knowledge lies behind the historic



concerns over deviltry and witchcraft. When the unshared knowledge is about other individuals it gives rise to concerns over privacy. Out of the problems of undisclosed knowledge there evolves in every society a set of values and practices which control what is considered to be private and what it means to invade privacy.

The development of a need for privacy is an important part of the process of socialization. In children the main mechanism for assuring compliance with social norms is surveillance. This creates in the child an early understanding of the desirability of seclusion. It provides a situation where one can behave in ways that would be or might be criticized. The 'might be' aspect of the child's situation is particularly important. No doubt children use privacy most often as a way of behaving in fashions where they are not sure whether or not they will be criticized. The mere fact of individual differences in behavior makes this basis for a need for privacy a continuing one.

As the individual develops, the internalization of social norms provides an alternative to external control. The greater the success of socialization the less society needs to oversee the behavior of the individual. This leads to a curious state of affairs in which the individual who needs privacy least is granted it most. In this sense privacy is a reward for responsibility. As with other rewards it is to be anticipated that this one will acquire incentive value, that is that it will become a motive. This process provides another source of a nee' for privacy.

In summary, then, a need for privacy appears to derive from three important facts of social life: 1) the existence of unshared knowledge of some people about others, 2) the ongoing conflict between idiosyncratic behavior and social norms and 3) the incentive value acquired by privacy as a reward for conformity to social norms.

Privacy and Sense of Self

In our culture the individual right to privacy is fundamentally connected to our views of human dignity, autonomy and personal worth. From the moment of birth



an important aspect of development is the process of separation of the individual from the social and physical environment. A by-product of this separation is a growing sense of being able to decide for oneself what one will and will not do in any situation. This in turn leads to the high value that we place on such self-determination. Thus privacy, in the sense of personal control, develops as a way of enhancing the self and protecting the self. Studies of the reasons people give for seeking and maintaining privacy reveal that these are attempts to protect and nurture or to extend and enhance the self. The perception that privacy is limited has been shown to be associated with lowered self-esteem. In the hands of the brain washers removal of opportunity of various types of privacy has been used as a way of breaking down the self.

Aloneness and Loneliness

The separation of the developing individual from the environment requires, by definition, that the child experience aloneness. How this condition comes about and how the child reacts to it are important factors in his developing concept of privacy. Children develop a concept of privacy fairly early. The four most commonly reported attributes of privacy are, in order, aloneness, controlling access to information, controlling spaces and "no one bothering me." At all but the very young ages the most frequent of these means chosen aloneness. The other attributes also contain this element of self-determination.

This emphasis upon chosen privacy flips the coin and reveals the other aspect of privacy. Aloneness that is not by choice is not a part of the desire for privacy. Loneliness, alienation, unsatisfied dependency and intimacy needs and despair thrive on privacy when it is not chosen. Here psychology entered the picture in an important way, in the writings of Sigmund Freud. After all is said and done, and after all the secondary considerations and evaluations of psychoanalysis have run their course, psychology and the world will owe a debt to Freud for having made one of the most important discoveries of modern history: that



And not that there are no qualifications. But never was that truth so fully explicated as it was by Freud and his co-workers. It is this finding, the finding that disclosure is therapeutic, that has informed virtually all the major therapeutic movements.

But disclosure also opens the individual to injury, and gives advantage to enemies. In a world in which enemies are not rare, the use of the method of disclosure for its therapeutic value opens the individual to new dangers. This dilemma is, of course, not new. It has been solved historically by the invention of the special relationship of professional to client. As we have seen this relationship is protected by law.

Situationality

That what privacy means to an individual is situation-bound should be obvious. But research is now beginning to expose the intricacies of this obvious point. Inevitably such relations end up telling us more about what is not known about the situational control of privacy than what is. At the present time this information seems to do little more than provide an explication of the many meanings of the more, "situation."

Physical Setting. As mentioned previously an early component of the child's concept of privacy in the control of access to space. This observation raises many questions, perhaps most importantly what makes a place a "private place?" It is a common belief, for example, that the bathroom is a private place. It has been found, however, that children and adolescents see the bathroom as private only in families with few members and with the lowest number of occupants per room. Along similar lines, for rural and suburban children, the outdoors is a private place, because invasion of privacy through surveillance is less likely to occur. For urban children indoors at home is the most available private place, but this means that invasion of privacy is more likely to occur.

Somewhat surprisingly, in fact (given all of the emphasis upon invasion of privacy in schools and therapy) the most common invasions experienced by children and adolescents

ur at home. The invaders are parents and siblings. Moreover, children see the

intrusions as malicious and deliberate. If nothing else the considerations brought forth in this section should sensitize us to avoid using any given situations or type of situation as a basis for defining privacy and the invasion of privacy.

Collectivities. Privacy, in whatever form, implies the existence of others and it comes as no surprise that emphases in the area of privacy depend upon the nature of the interactions among people in different groups. Moreover this consideration leads to the recognition that there will be a concept of collective privacy to deal with. For example the family is such a collectivity and families differ in the extent to which they are private entities. Some are open to other members of a community; others are closed.

The chief factor responsible for this difference appears to involve a relationship between the family and the larger community. If the larger community is relatively open, component collectivities will tend to be closed. If the larger collectivity is relatively closed, subcollectivities will be open. In an open society such as that in the United States this leads one to anticipate a heavy emphasis on privacy in the smaller groups represented by the church, the family, therapy and the school.

Culture. Returning to a treatment of individual privacy, different cultures have different patterns and forms of privacy. Through the process of socialization members of a society learn to identify, accept, and probably even feel private in situations defined as private by that society. For example there is community whose physical design is so open that all activities are open to the view of everyone else. As it happens that community prohibits extramarital sexual activity. So hencounters take place but in situations where they simply are "not seen" by other people. Apparently there is some sense in which these violations take place in private he it is a very different sense of privacy from that existing elsewhere in the world. These cultural interpretations of the concept of privacy are obviously an interesting topic for anthropological investigation. As yet, however, such research has to progress to the point where it provides coherent statements of how culture affects its members' concepts of privacy.

Invasions of Privacy and Self-Disclosure



Much of the emphasis in current thinking about privacy relates to the disclosure of personal information, most often by other individuals but sometimes by the individual himself. These two forms of disclosure are related to two established areas of psychological research, the psychology of self-disclosure and reactions to disclosures by others.

There is a great body of research in the first of these areas some of it involving laboratory procedures and some of it the methods of survey research. The picture is very mixed. We do know that trust in an interviewer, his sponsor, and the auspices under which the survey is conducted all play a role in determining what a person will disclose about himself. A part of this literature addresses such straightforward questions as the effects of anonymity of responses to questionnaires, the social desirability of called for responses and the like. A review of the data is far beyond our purposes here.

An aspect of this second question that deserves further study is the way in which people cope with the fact that the consequences of disclosure may occur some time in the future. Simply stated, "If I am seen doing this or that now, or if I am seen associating with this or that person, what are the consequences for me in the future in new situations?" There is a certain amount of literature on this question, too. For example positive future consequences lead to ready self-disclosure. We know very little, however, about the way in which people arrive at the decision that future consequences will be beneficial.

Where positive future consequences are not clear and disclosure is required (for example in the case of taking a personality test for a job) people sometimes resort to defensiveness and hostility and other protective stances which distort the assessment. At other times the individual may simply not do certain things because the distant consequences are unclear or sometimes because the current situation is only vaguely defined in its position on the public-private dimension. The crucial element in these cases is the predictability of consequences and in many cases the individual is unable to predict them.

Research on the effects of disclosure is not substantial. As mentioned in the last



section we know that people resent the collection of personal information about them and will forego needed services rather than provide such information for the record. We also know that this negative attitude toward invasion of privacy develops early. In one study of children 33% of the respondents described situations where information was revealed about them that they would have preferred to have kept to themselves, recalling their reactions in such terms as "anger," "hurt," "awful," "afraid," and "very upset." Beyond such scattered information there is little to report on this topic.

The reason for this lack of data is not hard to understand. In order to obtain the desired data experimentally, one would have to collect personal information on people with at least an implicit promise of confidentiality and then break that promise. Such procedures so violate the expectation of trust in human interaction that they would be hard to justify to one's conscience much less an institutional review board. Probably such data should be obtained in naturalistic settings through studies of the effects of unplanned disclosures.

Conclusions

This skimpy treatment of the psychology of privacy shows that the topic is a promising one for research in an area of great social significance. Although research has not accomplished much so far, interesting leads are opening up. These include clues to the origins of an individual need for privacy, a bit on the developmental aspects of this need, hints as to the various ways in which situational factors are involved in the development of behavior related to privacy and at least preliminary data on self-disclosure and reactions to disclosure by others. All of these topics deserve fuller investigation.

Perhaps with the following proviso: this section has treated privacy pretty much as if it were a single human condition or frame of mind, to which the individual has a sacred constitutional right, and as if everyone had agreed on what the concept of privacy means. Clearly this oversimplifies. Legal decisions distinguish between two aspects of privacy, personal autonomy and confidentiality. Analyses in terms of the facts and



concepts of social science will show that the concept has many additional aspects whose interrelationships remain to be determined. For example this report has hardly touched at all upon collective vs. individual privacy, territoriality and personal space, the invasion of privacy in psychological experiments and mental tests, or privacy as the concept relates to physical possessions as opposed to behavior, thoughts and emotions or relationships to family, friends, peers, superiors and colleagues. Obviously much remains to be done. Additional important topics will be mentioned in the last section of this report.



Protection of Privacy

The most important legal instrument created for the protection of privacy is the Federal Priacy Act of 1974. In order to reveal something of the intentions of this law as well as the issues it raises for professionals in many fields, it will be useful to look at some of its provisions. In the area of record keeping the major provisions are these.

- 1. There must be no personal data record-keeping systems whose very existence is secret.
- 2. There must be a way for an individual to find out what information about him is in a record and how it is used.
- 3. There must be a way for an individual to prevent information about him that was obtained for one purpose being used, or made available, for other purposes without his consent.
- 4. There must be a way for an individual to correct or amend a record of identifiable information about him.
- 5. Any organization creating, maintaining, using or disseminating records of identifiable personal data must assure the reliability (i.e., accuracy, relevance, timeliness and completeness) of the data for their intended use and must take precautions to prevent misuse of the data.

If these requirements were generalized to all record-keeping agencies, it would mean that any patient, consumer, or research participant would have access to his/her file. This does not represent customary practice. School psychologists have been reluctant to report IQs to children and/or their parents. Clinicians have been unwilling to share serious-sounding diagnoses like psychosis or organic brain disease with the person so diagnosed. Family therapists and social workers are unhappy about divulging observations about family members and their interactions. The reasons for withholding such information are many: 1) it will be misunderstood; 2) it will frighten or upset the client; 3) it will jeopardize the therapeutic relationship; 4) it is a tentative

diagnostic impression rather than an established fact; and 5) it may invalidate clinical testing tools for future use. On these grounds most clinicians feel that they should be allowed to exercise their professional judgment as to when and how much should be shared with clients. In some states, for example Ohio, this position has been reflected in privacy laws.

Dual Records

Where records are not protected by law in this way, a commonly proposed solution to the dilemna of sharing records is the maintenance of two files, personal records, which no one ever sees but the writer, and official records. The personal records contain conjectures, preliminary diagnoses, and impressions of which the psychologist is too uncertain to put them in the permanent file, which is reserved for more solid material. Attractive as the dual record system seems, most clinicians do not have the time or energy to maintain them especially in view of the increasing necessity of having "complete" official records in order to validate appropriateness of the intervention, progress, etc.

Transmittal of Files to Others

Several of the principles contained in the Privacy Act give the individual control over the decision to provide personal data about him to others. The usual means of implementing this principle is "informed consent." In order to be "informed," the individual must know what information is to be shared, with whom, why, and what the possible implications might be. Although this requirement is difficult to meet it states the ideal to be accomplished if possible.

In this same context there are the oft-repeated statements that only the minimum and relevant information required to meet legitimate needs should be released. Related to this is the idea that personal information should go only as far as absolutely necessary in the hierarchy of agencies that might request it. For instance, data necessary for reimbursement under any third party payment arrangement should be provided only to the immediate funding agency and that agency should have the responsibility



to keep the information confidential. In addition the recipient agency acquires the responsibility not to use (or allow the use of) this information for other purposes.

Time Limits on Retention

There are good reasons, in many situations, to plan for the disposal of records at the time of their collection. Test data and other personal information lose their validity over time and changes in the individual's situation may destroy the relevance of such materials.

There are, however, even better reasons for the preservation of records. It is hard to define the appropriate interval after which records should be destroyed, if only because it is impossible to predict which records will be useful later on. Dr. Alan Stone, Chairman of the American Psychiatric Association's Judicial Council, cited the example of recent research which established the connection between the stilbest-erol treatment of pregnant women and vaginal cancer in their daughters years later. If the mother's records had been stripped of identifying data, this and similar kinds of research could not have been done.

Assuring the Confidentiality of Research Data

The problem of assuring confidentiality of data is not limited to individual client records in clinical settings. It is a major issue in social experimentation and survey research as well. This fact was highlighted most recently during the Negative Income Tax Experiment, in which a county prosecutor forced economic researchers to yield research records on identified subsidy recipients (research participants). This case is a regrettable illustration that the researcher may be cast unwillingly into the role of informant, if the possibility of judicial or legislative appropriation of records is not anticipated. Such episodes make clear the need to work out strategies to reconcile differing standards on the need for information and the need for respecting individual privacy. Accommodating this dual task is difficult but there have been a variety of efforts mounted recently to do so. The major strategic approaches can be grouped into three broad categories—procedural, statistical and law-related.



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Procedural Strategies. Procedural approaches include the simple device of using alias identifiers. To accommodate some logistical problems, the link file system has been suggested in which a dictionary of double aliases is created and given for safe-keeping to an independent agency. If this agency is legally entitled to resist government appropriation of files, the procedure assures that identifiable records are secure from even governmental interrogation.

Statistical Strategies. The procedures just described are more apt to be useful in the impersonal forms of observation such as questionnaires, telephone interviews, and the like than they are in direct interview research. In research of the latter type it may be possible to use one of the statistical strategies that have been developed to protect privacy. One example of such a strategy is the randomized response tactic currently under test and development in several parts of the world. In the simplest variation, the social scientist simultaneously presents a sensitive inquiry to an individual, e.g., "Did you cheat on your income taxes this year?" and an insensitive one, e.g., "Do you prefer potatoes over noodles?" The roll of a die determines which one of the respondent will answer. When the process is carried out on two large samples, it is possible to estimate the proportion of individuals who have cheated on their income tax forms and the proportion who "prefer noodles?" Given some simple laws of probability, the odds on answering one or the other question, and the observed proportion of 'Yes' responses, the estimation is a matter of simple algebra.

Another statistical approach is based on aggregation of response. The individual is asked not to respond individually to each of a set of questions but to respond in aggregated form to the set. Two samples are necessary. In one, the individual is asked to add the numerical values corresponding to his responses and in the other, the individual subtracts the values of his responses. This gives two independent equations, each with two unknowns, which provide sufficient information to estimate the mean response separately for two individual questions. This technique permits one to elicit even sensitive information in direct interview situations without any deterministic



linkage between an identified response to the researcher's questions and the actual status of the individual.

The third and final class of statistical techniques which has received some attention is aggregation of the sample. The technique requires that one obtain data not on a single identified individuals but rather on very small and carefull constructed clusters of individuals. If the cluster's composition remains the same over time, each cluster can, under certain conditions, be regarded as a synthetic person, a composite of all the properties of the small set of individuals it comprises. Some information data analyses can be conducted on those aggregates and, insofar as aggregation helps to assure anonymity of individual response, there is no depreciation of individual privacy.

Law-related Strategies. The final class of approaches to protecting individual privacy in social research involves formal legal action by legislators, the courts, or governmental agencies. Such action is taken to assure that when identifiable data must be collected for research purposes, the data will not be used for purposes other than research. For example, the 1970 Drug Abuse Act and the 1970 Alcohol Abuse Act both permit the Attorney General to accord privilege to social scientists who are funded by the government to conduct research on those topics. Under the Public Health Act, persons engaged in research on mental health, including the use of alcohol and other psychoactive drugs, can be accorded privilege by the Secretary of Health, Education, and Welfare to protect the privacy of individuals who are subjects of such research. These are new laws, enacted specifically to assure the confidentiality of social research records on identifiable individuals. They define a limit of the government's power to obtain access to social research records. They also put a limit on the conditions under which the researcher may act. They represent a spirit of support for the social sciences as well as an appreciation for the negative impact which even legal appropriation of research records may exert on policy relevant research.



Recommendations

The previous pages have made a brief presentation of the current situation in the area of privacy. We have seen that concern for privacy is an expression of an important human need. In recent years this concern has become a very important one because of technological developments and a loss of faith in institutions. One of these institutions, government, has created well-intentioned laws designed to protect the individual from unwarranted invasions of privacy. Although the objectives of such legislation are ones with which we are in sympathy, the consequences have not been entirely good. Privacy laws affect the activities of psychologists in most of their usual functions. This means, that for the good of psychology as a science and a profession, the official organization of our discipline should maintain surveillance over the developments in the area. Some of the specific actions which the Association might take along these lines are recommended in this final section of our report.

These recommendations fall into six categories: 1) policy of the American Psychological Association, 2) research on privacy and confidentiality, 3) legislative activity, 4) review of ethical principles on privacy and confidentiality, 5) informing the membership of APA, and 6) continuation of APA's involvement in the topic.

Policy of the American Psychological Association

Consider the following case involving an issue of privacy. A researcher, with MA level training in an area not relevant to the research he proposes, accepts a contract from a drug company, to demonstrate that scores on a certain personality test will predict later drug abuse. Those with any knowledge at all about the test or drug abuse know that the research is pointless. The test has little reliability and is unlikely to predict anything.

Nevertheless, the study gets under way. The investigator, however, commits what appears from newspaper accounts to be a clear violation of our ethical principles by circulating personally identified scores widely, labelling some of the research participants as potential drug abusers. The case receives wide public attention when a parent



of one of the labelled children brings suit against the investigator--identified in the press as a psychologist--and his sponsor.

Question: What is APA's responsibility in this situation?

Clearly it would be wrong for the Association to take a position for or against the investigator in this case. That would be an unjustified assumption of innocence or guilt. On the other hand there is reason to believe that the public tends to generalize from one member of a profession to all members. Thus, convinced this psychologist The public might conclude that released damaging information about people./all psychologists do the same thing.

Such a public reaction would be unfortunate, especially in view of the decades of work committees of APA have done to create ethical guidelines that cover cases such as the one described. Since these guidelines exist it seems proper that APA make its position known when such public information appears likely to benefit the science and profession of psychology.

Association should create or strengthen mechanisms for stating psychology's position in connection with widely publicized invasions of privacy and other infractions of our ethical guidelines. The responsibility for implementing this guideline appears to lie in the Central Office of the Association.

Although this recommendation limits itself to statements of ethical position, what is involved is obviously a more general issue. The same mechanisms might come into action in any incident that receives heavy coverage in the media and appears to affect the status of psychologists and psychology.

Addendum. The question of what happens to the specific individual in this case raises two issues that deserve study but where no recommendation seems possible. The researcher was almost certainly not an APA member and probably not a member of a Stite Association. Thus he is beyond the reach of the committees on ethical conduct of these organizations. The first question, thus, is what type of control the Association can exercise or wants to exercise over professional psychological activities by people other



than its members.

The second question has to do with cases where APA members are involved in charges of violation of our ethical principles. In many of these cases there is a referral to the ethics committee of a State Association. Almost never, however, do the records show what happens in such cases. Perhaps a means should be developed for following up on such cases and making outcomes a matter of record.

Research on Privacy

As public interest in the protection of privacy has grown the topic has become an area of investigation. Unfortunately, the amount of work being done is still small. More research could be of great usefulness. New information systems and technologies are developing and their use is expanding. Although laws and codes of ethics that are responsive to this state of affairs are necessary and being created, these activities are without a background of pasic information to guide them. Consequently laws and ethical codes may either underestimate or overestimate the importance of privacy and the significance of its invasion in various situations. The importance of the issues and the fact that sound data should be of value lead to the following recommendation.

Recommendation II. The American Psychological Association should use its official voice and devote some of its resourses to the encouragement of research on privacy and confidentiality.

One very specific way in which APA might have an influence would be by bringing the desirability of such research to the attention of funding agencies. In various ways, research on privacy is clearly relevant to stated national priorities. The inclusion of privacy research in lists of examples of work for which funding is available, by NIH and ADAMHA, would probably bring an immediate return in terms of applications.

Some of the topics that are interesting and important have alread, been mentioned. The following list sometimes repeats these topics; others are mentioned for the first time. Obviously the list is neither ordered nor exhaustive.

1. Demography of the concept of privacy. How does this concept vary with age,



sex, socio-economic status, ethnic group, profession and the particulars of situations?

- 2. <u>Effects of disclosure</u>. How do people react to unwanted disclosures of information about themselves?
- 3. Effects of disclosure on therapy. What would happen if clients had access to their own records? What effect does the knowledge of disclosure of this information to others have on therapy?
- keep information about themselves secret?
- 5. <u>Individual differences</u>. Is it true as sometimes said that people with privacy assured have high self esteem? Or is it perhaps the other way around, that people with high self esteem have less of a need for privacy?
- 6. <u>Processing personal information</u>. When one finds out something personal about another individual (or himself) how well is that information comprehended? How does the retention of such information change in time? These are all questions where experimental and social psychology have information for some types of materials. Are results the same with personal knowledge?
- 7. <u>Developmental factors in creating a need for privacy</u>. Some data would suggest that criticism and punishment would foster this need. Right or wrong? If right, given this tie between privacy and responsibility such data might alter popular beliefs about the effects of punishment.

Putting these suggestions in the form of questions is merely for the purpose of identifying areas for study. Actual research would of course look at the effects of important variables upon the processes in question.

There is also a different type of research which APA itself might carry out. This would be research to determine how the privacy situation is affecting the activities of psychologists. A major study of this type would involve another investigation of the type previously used to obtain the materials that have led to the development of APA's various sets of ethical principles. This time, however, the focus of the study would be



in the area of privacy and confidentiality. A smaller, related, study might attempt to find out something about the kinds of information which various agencies have on psychologists. Several members of the Task Force attempted to obtain such information, chiefly from the CIA and FBI, but without much success. The FBI usually responded with a report that there were no files on the member making the request. The CIA asked for formal, notarized, proofs of identity, which actually do not seem unreasonable, but were enough to discourage action on the part of busy people. Obviously such a study raises its own questions about the invasion of privacy and the maintenance of confidentiality of research information.

Legislative Activity

As we have seen privacy and confidentiality are continuing foci of legal activity. Every year new court cases involving these issues are settled and the legislation is created. This is as it should be. In the long run the most effective way for psychology to have its interests supported is to have such support written into law.

At the present time the chief concerns of psychology (and probably the health professions and sciences generally) are to maintain confidentiality of information where that is required and to be allowed access to information in other cases.

Certain desirable aspects of privacy legislation that might help to meet these concerns are presented in three recommendations to follow. A more general recommendation is obvious: APA should maintain contact with legislators urging the inclusion of these features in any new privacy acts. In this connection it is worth mentioning that a new profession appears to be developing, for which a few training programs now exist. These programs prepare social scientists to serve as members of legislators' staffs. Contacts through such people may be more effective than contacts directly with the legislators.

Recommendation III. In those areas where statutory protection for clinical-therapeutic and other personal data exists that protection should be strengthened and refined.

Legal testimonial privilege, for example, is available in some states, for some



categories of psychologists. That statutory protection is often very weak, however, in the sense that exceptions are numerous and the language of the statutes ambiguous. Where possible, such laws ought to be revised to reflect the ethical concerns of clinical psychologists more clearly and the statutes should be clarified.

The refinements mentioned in the recommendation refer to a distinction made in the Key Biscayne Conference on Confidentiality of Health Records between records obtained for evaluation on the one hand and treatment on the other. Information of the first type is usually less sensitive than information of the second type. In child custody disputes, drug treatment programs and civil commitment procedures, evaluators would be free to reveal necessary and pertinent information. Once decisions were made on the basis of such information, treatment would follow more stringent rules of confidentiality.

Recommendation IV. In those areas where administrative records are protected by law, the law ought to be refined to recognize that in many instances those records serve as a basis for important statistical research.

The discovery of the connection between stilbesterol treatment of pregnant women and vaginal cancer in their daughters later on, mentioned earlier, illustrates the importance of maintaining such records with identifiers attached. Statistical research rarely constitutes a real threat to privacy and may bring great scientific and social benefits. Unfortunately the new privacy legislation has made the bureaucrate in charge of records very conservative about releasing them. There should be revisions of the privacy laws that bring a recognition of the minimal risk. Moreover, the laws should be construed so as not to discourage legitimate use of records for purposes of research.

Recommendation V. In those areas where statutory protection for research records exists, the statutes should be strengthened and refined.

As mentioned earlier a legal testimonial privilege is available for researchers conducting investigations in certain areas, most notably, drug abuse and alcoholism.

Those laws are strong to the extent that they recognize the serious problem of government appropriation of records and protect the investigator against it. They are weak



in some instances, however, because the protection is so limited as to provide little or no real protection. For example the identity of the research participant may be protected when the raw data are not. The Drug Abuse Office and Treatment Act of 1972 says that the identities of research subjects shall be confidential and protected against subpoena. But, if a prosecutor already knows the name of a subject, he can subpoena all the data on that individual. Loopholes of this type in laws designed to protect the individual subjects need to be closed.

Review of Ethical Principles

A part of the charge to the Task Force on Privacy and Confidentiality was to make recommendations of "guidelines relating to specific issues within these areas (to be) presented to the Association for action." The following recommendations do this but they may create a problem. The APA ethical guidelines are currently undergoing revision and this revision could conceivably run counter to what we propose. Although the Task Force kept in contact with the Committee revising the ethical principles, the revision had not been completely worked out when this report was written. For this reason the following recommendations must be considered against the proposals of other groups in APA working on the same task.

Recommendation VI. In cases where a therapist could also be involved in administrative decisions about a client the therapist should, if possible, remain apart from the administrative decision.

Suppose that a clinical psychologist in a university psychology department has as a client a graduate student in that department, that a decision must be made about dismissal or retention of the student and that the decision is a difficult one. In such a case it would be very difficult for the therapist to remain objective and he or she should not participate in the decision.

If as in the case of parole reviews the therapist must participate in the decision, the distinction between evaluation and treatment may be helpful. The therapist should limit himself to the role of evaluator.



Recommendation VII. Personally identified mental health information should be retained by the facility that obtained it. No other agency should be allowed access to information in this form.

There will of course be situations where exceptions to this principle are proper and necessary. Obviously those who are paying out money need to know that the client whose treatment is being paid for was in fact in need of those services, and for the time that they were provided. This means that it will be necessary to disclose the client's name and such diagnostic and treatment data as are required to prove eligibility.

In addition to the exception suggested by the needs of third party payers, there are two others. The first involves in-facility research and follow-up on clients. Most often this is essential for quality appraisal of treatment; and insofar as assuring quality does form part of the treatment enterprise, we see no serious issue in disclosing records to the legitimate in-house researcher for that purpose. Research by outsiders on the quality of treatment, effect of treatment modality, and so on, may have exactly the same purposes and exhibit the same negligible threats to the privacy of the individual. The facility should take major responsibility for serving as intermediary in such cases, especially where it is clear that the scientific benefits of the research offset any discomfort to clients.

Such exceptions should be made only when a careful balancing of the need for disclosure against privacy interests clearly warrants the exception. In making this determination, a variety of factors should be considered, e.g., whether the purpose of disclosure could be substantially served by means that do not involve identification of the client, whether disclosures would be limited to absolute necessity, both in terms of the nature and amount of the information to be revealed and the persons and organizations who would gain access, whether the recipient would provide appropriate safeguards again the further disclosure, and whether the recipient would retain the information after the purposes of disclosure has been served.

Exceptions based on client consent should provide guarantees of the voluntary and



informed qualities of consent. When the client is under some coercion--for example, when consent is required for the provision of or reimbursement for treatments--rules (laws and regulations) to protect the client from exploitation may be appropriate. For consent to be sufficiently informed it should generally entail access to and knowledge of the information being disclosed.

Informing the Membership of APA

Because of the salience of the issue of privacy these days many psychologists are worried about their positions and practices as regards the maintenance of the confidentiality of data. For example many psychologists are not clear on such matters as the extent to which their records have legal protection. Such problems arise with some frequency in the day-to-day activities of psychologists. The clinician may be told by a client that the client intends to commit a major crime. Information that comes up in the course of research may arise serious questions about the mental health of particular subjects. Many psychologists seem poorly prepared to deal with such problems.

Recommendation VIII. Possibly through the creation of a new section in the

Monitor a forum should be established for the discussion of practical ways of resolving

problems which bear on the confidentiality of personal information and the privacy of the
individual.

Whether in the Monitor or somewhere else, the purpose of this forum would be to provide a way for the psychologists to share experiences in the area of privacy and confidentiality. Problems and solutions to problems would be the major topics of discussion.

Recommendation IX. As practical experience in the area of privacy accumulates, APA should commission the preparation of a Casebook on Confidentiality where concrete examples of dilemnas and solutions could be made available to the membership.

Probably some of these materials are already available in the file: of the Cook

Committee and the Hobbs Committee. Other materials would become available if the recommendation to make an empirical study in the area of privacy and confidentiality is accepted.

Recommendation X. Sophisticated techniques now exist for the collection of



sensitive data in ways that insure respondents' privacy. These should be brought to the attention of people in the field.

Some of these methods were mentioned in the earlier section on Protection of Privacy. As the few examples alluded to there may suggest, however, these techniques vary a great deal depending upon the type of research. Thus the materials "brought to the attention of people in the field," as recommended here, should be the specific materials that are relevant to specific research areas.

APA's Continued Involvement

With the submission of this report the present Task Force on Privacy and Confidentiality asks to go out of existence. Our experience has convinced us, however, that the work of the Task Force should continue and that APA should maintain an involvement in the area.

Recommendation XI. The Board of Directors of the American Psychological
Association should appoint a new Task Force on Privacy and Confidentiality.

Several characteristics of this new Task Force seem clearer now than when we began.

- 1. The charge to the Task Force should be relatively focussed. Legal aspects of the issue, fostering research, doing a survey of problems and practice in the area and informing the membership of APA--but not all of them--are possible foci.
- Membership on the Task Force should be appropriate to the established focus.
 - The term of appointment of the new Task Force should be three years.
- 4. A budget sufficient for two meetings a year for two years and three or four meetings for the third year should be provided.
- 5. Staff assistance of the type provided us by Fred Strassburger is essential to the work of the Task Force and should be continued.



Recommendation XII. This Task Force on Privacy and Confidentiality should be dismissed. This report or some summary of it should be made available to the membership of the American Psychological Association and to the people in other fields concerned with these issues.

